October 3, 2013

Chairperson Pilcher-Cook and Committee Members

Thank you for the opportunity to comment today on our observations regarding quality and access issues within the KanCare program. I am Mitzi McFatrich, executive director of Kansas Advocates for Better Care (KABC). KABC is a not-for-profit organization, which advocates on behalf of frail and older adults and has since 1975. KABC does not provide any form of direct care or services. We are an established resource for consumers on aging and long term care issues. Most of the calls and requests for information that we receive come from persons or families who are facing difficult and life-changing decisions about long-term care and need immediate help.

Since Jan. 1, 2013 we have received numerous calls from older adults and adults with disabilities and their families related to KanCare. The number of calls continues to increase steadily. Quality issues related to reduction in services for persons on HCBS waivers have been a central theme among many of the KanCare-related calls. Consumers and families also are voicing concerns about access to case managers and most are looking for help self-advocating within the new system. The following examples illustrate the issues that are being shared with us by consumers.

Nursing facilities:

- A small, random poll in June of nursing facilities (large and small; urban and rural) across Kansas showed that several had not been contacted by staff or case managers from any MCO. One had been visited by one MCO representative who spoke with staff but not with residents. One MCO's case manager visited one of the facilities and spoke with three residents. One MCO sent a representative to make copies of resident files but did not talk with staff or residents.

Home & Community Based Services:

- Weekly assistance for an elderly woman with dementia and uncontrolled continence was cut from 40 hours to 10. When interviewed alone by the case manager, the woman told the case manager she could manage daily activities that in reality, she could not. The case manager did not contact the family (employed but providing significant amount of care) before recommending the cut in hours. After the family appealed to the case manager's supervisor and set up a second, unannounced visit to the home, the woman's weekly assistance was reset to 30 hours –still 10 hours less than she received before KanCare.
- A 54-year-old woman needed in-home services after the amputation of her leg. Due to cuts in staff, the local center for independent living could not serve her. When she contacted the ADRC-Aging & Disability Resource Center, she was told that the Area Agency on Aging could not help her because she was not 60 years old. Her MCO told her, it could not help because she had a "caregiver" in the home. The "caregiver" was a friend who had come from Dallas to help following her friend's surgery and was returning to Dallas within a few days. The consumer had never been contacted by a case manager. KABC referred her to the KanCare Ombudsman's Office and the Disability Rights Center.
- A woman who herself has serious heart disease and is a full time caregiver for two family members, her 90-year-old mother and a son in his 20's who has serious persistent mental illness. When her son was having a serious mental health crisis, she phoned the MCO and told them her son was in crisis and she needed immediate help. 72 hours later the MCO representative returned her call, but could not offer any help beyond the options in the

printed manual, all of which the woman was aware of or had already tried. She was left to manage as best she can, on her own. At the time of the call, four months into KanCare, the caregiver's mother, who received services under the HCBS/FE waiver, had not been seen by a case manager.

- A woman in her 40's, receiving services under the HCBS/PD waiver had three case managers in three months through two MCOs. She changed her MCO during the first 90-day choice period when the first case manager was unresponsive to her needs. Her second case manager quit not long after being assigned to the caller. She had just started with the third case manager when she called KABC.
- We have had numerous calls about problems with transportation issues, including lack of transportation to adult day services for an elderly woman with advanced dementia. The calls we have received are similar to those expressed during the Rapid Response period and documented in both quarterly reports to CMS.
- KABC regularly refers consumers to the Office of the KanCare Ombudsman. Three callers told us that they had contacted the Ombudsman's Office, but after three months and repeated contacts, their issues remained unresolved.

The consistency of stated problems and the increasing volume of calls, validates that the problems are not uncommon, nor isolated. While there is a learning curve and a transition period with a system change of this magnitude, what Kansas currently has is at best piecemeal approach to building an adequate consumer support and information network. And the current network as it is pieced together does not appear to be strong enough to provide adequate or effective protection for consumers.

Advocates and policymakers need an adequate amount of detailed, meaningful data not currently being gathered and tracked within KanCare. This data is key to assuring that consumers are able to access and utilize the quality support services and health care they need.

The consumer-specific data in KanCare is limited and makes it difficult to get a clear, full picture of the program's impact on long term supports and services.

Program Utilization data is needed and when combined with information tracked through the ombuds office and an evaluation tool that comprehensively assesses the quality of the services provided and measures access in meaningful ways, we will have a realistic and complete picture about the effectiveness of KanCare in meeting its stated goals.

The ombuds program is one entity which might provide timely, relevant and specific consumer information. The baseline data being tracked through the KanCare Ombudsman's Office:

- Does not provide enough detail to assess the impact of KanCare on consumer members' health and support services;
- Compresses concerns into five or six very broad areas and combines grievance and appeals with billing and claims issues (as data is reported to CMS);
- Is not detailed enough to identify trends in consumer outcomes and services;
- Is further diminished with the "increased reliance of appropriate delegation to routine & administrative inquiries," because once a contact has been delegated there is no process for following up;

We know consumers are raising concerns, but what assistance are they receiving?

- Response time of the KanCare Ombudsman doubled from 4 hours to 8 hours from the first quarter to the second (report to CMS);
- 6% decrease in resolutions (same report);
- Standard of "resolution" is too low - defined as when the "consumer's question was answered." We would recommend that KanCare expand the definition of "resolution" to include input from consumers by developing a process to follow-up with persons who contact the Ombudsman's Office for help.
- Unable to track the quality of the care consumers receive and their ability to access that care based upon reporting of Ombuds program.

KanCare Reports

- do not show basic program utilization data – i.e. number of members whose care plans have been cut, reduction of care hours, average number of hours reduced, or which services are cut;
- do not break down data by waiver population.

KanCare Evaluation

- The survey instrument does not collect information about consumers' satisfaction with the overall KanCare program, case manager services or long term support services, such as transportation.
- The State's evaluation plan as drafted will not give us any deeper insight into the ombuds data. Requiring only a review of the ombuds program's reports. The evaluation plan compares and tracks the number of grievances, again, without any insight into the reasons prompting consumers to file a grievance.

Recommendations:

1. Basic Program Utilization Data –
   - cuts to care plans, hours, and services
   - by waiver population groups
2. Ombudsman Program Data –
   - detailed enough to identify trends in consumer outcomes and services
   - strengthen the "standard of resolution" and provide for consumer input/evaluation of the assistance received
3. Evaluation Instrument and Data –
   - collect information from consumers regarding satisfaction with and effectiveness of KanCare program and services, including ombuds services
4. Strengthen processes for consumers to provide feedback about quality and access –
   - including through a functioning KanCare Advisory Council,
   - recommendations from the Consumer & Specialized Workgroup, and
   - functioning MCO Consumer Councils

Thank you for your consideration of our remarks.

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